Missouri Statewide Health Information Exchange
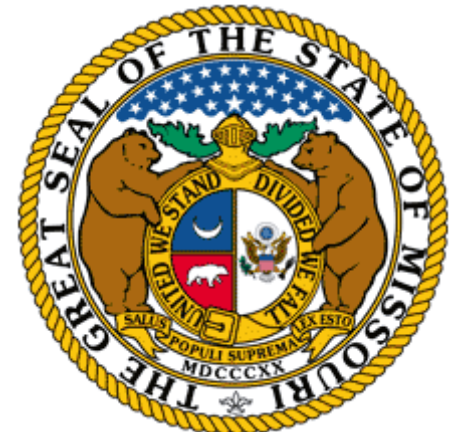
Consumer Engagement Workgroup

February 10, 2009

11:30 am – 1:30 pm

Jefferson City, MO

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Agenda

Topic	Facilitator(s)	Time
Welcome, Introductions & Meeting Objectives	Co-Chairs	11:30 – 11:45 am
Meeting & Webinar Recap	Co-Chairs & Manatt	11:45 – 12:00 pm
MO-HITECH HIE Draft Strategic Plan & Project Budget	Co-Chairs & Manatt	12:00 – 12:15 pm
Missouri Initiatives "Panel"	All	12:15 – 1:15 pm
Intersection with Legal/Policy	Co-Chairs & Manatt	1:15 – 1:25 pm
Operational Planning & Next Steps	Co-Chairs & Manatt	1:25 – 1:30 pm

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Governor Nixon's Vision – Six Objectives

1. **Improve the quality of medical decision-making and the coordination of care;**
2. **Provide accountability in safeguarding the privacy and security of medical information;**
3. **Reduce preventable medical errors and avoid duplication of treatment;**
4. **Improve the public health;**
5. **Enhance the affordability and value of health care; and**
6. **Empower Missourians to take a more active role in their own health care.**

Thank you for partnering with the state in taking critical first steps in building a new framework for health information technology in Missouri

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Meeting Objectives

- ➤ **Review updated draft HIE Strategic Plan**
- ➤ **Segue into Operational Planning**
- ➤ **Hear from Missouri initiatives engaging consumers**
- ➤ **Understand overlapping issues with Legal/Policy Workgroup**

Meeting Recap

- ➤ **Content Reviewed**
  - Meaningful Use discussion
  - MO-HITECH Draft Strategic Plan
  - Key principles
  - Consumer Engagement Strategy Development
- ➤ **"Consensus" Recommendations**
  - Consumers should be part of the Statewide HIO and be formally represented on the Board
  - There is a need for continuing education; consumer engagement and education should be ongoing and not finite within the current process
  - Consumer access to health information should be meaningful
  - Individuals should be notified of security breaches or privacy violations and have access to safeguards and enforcement
  - There should be a Consumer Advisory Council established to inform and advise the Statewide HIO and its Advisory Board

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MO-HITECH Draft Strategic Plan

- ➢ **Specify focus on *personal* health information**
  - Versus aggregated, de-identified information
  - E.g. Individuals should have secure, convenient access to their ***personal health information***, including access by a designated proxy.
- ➢ **Consumer engagement strategy augmented to include consumer representation on the Board of the Statewide HIO**
  - *Ensuring consumers have strong representation on the Board of the Statewide HIO*
- ➢ **MO-HITECH Advisory Board reviewed Strategic Plan and supported consumer engagement and role of consumers on the Board of the Statewide HIO**

Segue into Operational Planning

- **Strategic Plan will be iterated based on Workgroup, Advisory Board, and stakeholder feedback through February**
  - The Strategic Plan sets out an approach to address unresolved issues/questions through the Operational Planning process
- **Segue into Operational Planning to address**
  - Consumer engagement strategy
  - Legal/policy issues
  - Budget allocation for consumer engagement activities and staff
- **Develop project work plan, milestones, and associated budget**
  - Identify consumer engagement activities
  - Assign estimated costs (price range) to activities
  - Prioritize activities based on available funding
- **Strategic Plan will be updated as appropriate to incorporate decisions from Operational Planning process**

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Project Tasks & Timeline through May 2010

State HIE Grant Application

- **Letter of Intent Submitted**
- **Project Initiation**
- **Begin Landscape Assessment & Interviews**

Strategic Plan

- **Submit Application to HHS**
- **Executive Order 09-27**
- **Statewide Kickoff Meeting**
- **Publish Draft Strategic Plan for Review/Comment**
- **Submit Strategic Plan to HHS**

Operational Plan

- **Submit Operational Plan to HHS**
- **Publish Draft Operational Plan for Review/Comment**

Sept	Oct	Nov	Dec	Jan 2010	Feb	Mar	April	May

- Support State application process
- Conduct stakeholder interviews

- Establish MO-HITECH
- Establish Advisory Board
- Convene Workgroups
- Draft Strategic Plan
- Publish Draft Strategic Plan for Review
- Develop detailed project timeline and work plan
- Engage and educate stakeholders

- Convene Advisory Board & Workgroups
- Draft Operational Plan
- Publish Draft Operational Plan for Review
- Update project timeline and work plan
- Engage and educate stakeholders

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Consumer Engagement Webinar

- **Josh Seidman, ONC**
- **Mike Kirkwood, CEO, Polka & Co-Chair, California Patient Engagement Workgroup**
- **Julie Murchinson, Managing Director, Manatt Health Solutions & Staff, California Patient Engagement Workgroup**
- **Andrea Routh, Executive Director, Missouri Health Advocacy Alliance**

Access Webinar audio recording and materials online at http://dss.mo.gov/hie/leadership/index.shtml

Josh Seidman, ONC

- ➤ **For patients and their families, meaningful use is about**
  - Communicating with your providers
  - Accessing important, relevant health information when, where & how you want it
  - Better managing your health & health care
- ➤ **Principles for real consumer engagement**
  - Education is bidirectional (multidirectional)
  - Solicit consumer input before planning outreach/campaign
  - Design HIE to meet their needs for information flow
- ➤ **Understanding consumers**
  - Consumer surveys
  - Consumer focus groups
  - Structured interviews
  - Ethnographic observation
    - ○ Shadowing patients and clinicians
    - ○ Shadowing consumers in their daily lives

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Seasonal View of Meaningful Use

Snow   Meaningful Use of Snow

California Patient Engagement Workgroup
Mike Kirkwood & Julie Murchinson

➢ **How do we earn the trust of patients (and families)?**
  - Control
  - Transparency

➢ **What really engages a patient?**
  - Awareness
  - Provide value (make it easy, compelling, interesting)
  - Representation in process
  - Health system touch points
  - Natural consumer touch points
  - Two-way street (consumer-driven data and provider-driven data)

➢ **What tools work for patients? PHR?**
  - Let the consumer decide
  - Encourage innovation around the consumer

➢ **How do we know if we are engaging patients?**
  - Outreach metrics vs. patient use metrics

➢ **Is a patient a consumer (and vis versa)?**

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Andrea Routh, Missouri Health Advocacy Alliance

➢ **Groups that should be engaged**
- Rotary
- Elks Club
- Veterans of Foreign Wars
- Unions (e.g. Postal Workers, United Auto Workers, etc.)
- League of Women Voters of Missouri
- Faith-based groups, churches, and synagogues
- AARP (teleconferencing)
- Coalitions (e.g. disability advocates, mental health advocates)

➢ **Points of engagement**
- Parish picnics
- County & State fairs

➢ **Social & traditional Media**
- Radio networks and talk shows
- Public television

➢ **Missouri Foundation for Health retreat**

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National Update – HHS Federal Grant Announced

➢ **HHS will contract for technical professional services to support a comprehensive, multi-faceted campaign that fulfills the Health Information Technology for Economic and Clinical Health (HITECH) Act mandate to provide public education about the privacy and security of protected health information**

➢ **The campaign seeks to reach consumers, patients and health care providers to:**
- Build approval for health IT adoption and meaningful use
- Increase patient and provider participation in electronic health information exchange
- Educate the public about the uses of personal health information and privacy and security protections available to them
- Generate participation in HITECH programs (e.g. loans, grants, and contracts)

➢ **A comprehensive, integrated approach to successfully communicate about privacy, security and meaningful use to target audiences in creative, meaningful ways**
- Activities could include, but are not limited to, targeted paid advertising, earned media support and grassroots outreach

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Missouri Initiatives Engaging Consumers

- Health Care Foundation of Greater Kansas City
- Missouri Foundation for Health
- Health Literacy Missouri
- CareEntrust

Health Care Foundation of Greater Kansas City (HCFCKC) Community Advisory Committee (CAC)

➢ **Structure – Up to 24 members designated by Appointing Authorities**
- Mayor, Kansas City, MO appoints =8; Mayor, Independence, MO =3; Jackson County, MO County Executive =3; Johnson County, KS County Commission =3; Mayor, Iola, KS =1; Mayor, Lexington, MO =1; Mayor, Lee's Summit, MO =2; Mayor, Harrisonville, MO =1; Wyandotte County, KS Unified Government =1; Mayor, Belton, MO =1

➢ **CAC Committees**
- The Community Input Committee's primary purpose is to assure that the HCFGKC is informed and responsive to community health care needs through its organizational conduct, in particular its grantmaking process. Strategies include: (1)Public Forums/Community Listening Sessions; (2) Issue Forums and (3) Annual Report.

- Nominating Committee – Interviews and selects a slate of candidates to fill Board positions, which are then voted on by the Board of Directors

- Review Committee – Provides community feedback to the HCFGKC Board of Directors on the impact of its policies and programs on the community. Furthermore, it provides the Board with the committee's perspective as to future actions and emphasis for the corporation

Missouri Foundation for Health Community Advisory Council (CAC)

➢ MFH is Missouri's largest health foundation and the nation's third largest health conversion foundation, with a mission to focus on the uninsured, underinsured and underserved within its 85-county service region

➢ The Consumer Advisory Council (CAC) is a 13-member group that serves as an advisor to MFH's Board of Directors

➢ CAC Roles and Responsibilities

- Serves as a link to the community and conducts fact-finding activities to assure MFH's funding is responsive to community needs
- Reviews the effectiveness of MFH activities, and provides community-focused counsel to the Board and staff
- Annually the CAC identifies and nominates candidates for the Board
- CAC members serve unpaid 3-year terms, and are expected to attend CAC and committee meetings, usually in St. Louis, plus represent MFH throughout the service region
- Members are expected to be interested in and understand health issues affecting Missouri

Health Literacy Missouri

- ➢ **Mission: To improve the health status of all Missourians through**
  - Increasing awareness of the role health literacy plays in the health of Missourians
  - Fostering collaboration and coordinating resources and efforts among diverse organizations across the state
  - Providing a clearinghouse of resources, technical assistance, policy analysis, education, and outreach
- ➢ **Outreach through**
  - Social media – Twitter, LinkedIn, Facebook, Podcasts
  - Demonstration projects – LIFT, YMCA Literacy, Seed to Table, Health Empowerment Parties
  - Community health literacy activators
  - Health literacy at a grass roots level

Health Literacy Missouri

➢ **Products and Services**

- Plain language review and translation
- Provider training modules
- Clinical Simulation Center training module
- Standardized physician training
- Transformation team

➢ **Policy Impact**

- Health care reform
- MO-HITECH

CareEntrust Profile

- Charter: ***the delivery of an electronic health record for consumers and their providers to use in improving the continuity of care***
  - Transcends organizations, care settings and payers over time
  - Personally controlled by consumers/patients
- First employer-sponsored health information exchange in the country
- Established 2006, system live in May 2007, received "HIE 501(c)(3)" in July 2009
- System includes clinical, claims (procedures & drugs) and patient self-entered (eClipboard) data – 43 data sources, 67 interfaces
  - Both consumer/patient and physician views into same longitudinal health record
- Selected CareEntrust metrics snapshot:
  - 24 employer sponsors including hospital systems, Federal Reserve Bank, State of KS, health plan and large KC-based companies such as Sprint, Cerner, H&R Block
  - Over 4.5M transactions processed and available within the system today
  - One of the top national consumer/patient adoption rate leaders at 17%
  - System opt-outs less than one half of 1%
  - **85% of consumer/users say the "CareEntrust Health Record adds value to the management of their health care information"** (survey conducted January 2010)
- Current sponsors represent collective <u>annual health care spending of $428M+</u> within the KC area

What Is a Personally-Controlled Electronic CareEntrust Health Record (CHR)?

- Consumer/patient-centric repository for clinical and administrative health information
  - Transcends organizations, care settings and payers over time
  - Personally controlled by consumers/patients
  - Ability to upload and fax documents into your record

- A secure tool which allows both providers and consumers/patients to access:
  - ✓ Past and current medications (plus ePrescribing capabilities)
  - ✓ Lab results
  - ✓ Visit history/procedures
  - ✓ Immunizations
  - ✓ Vital signs
  - ✓ Demographics information (eClipboard)
  - ✓ Allergies
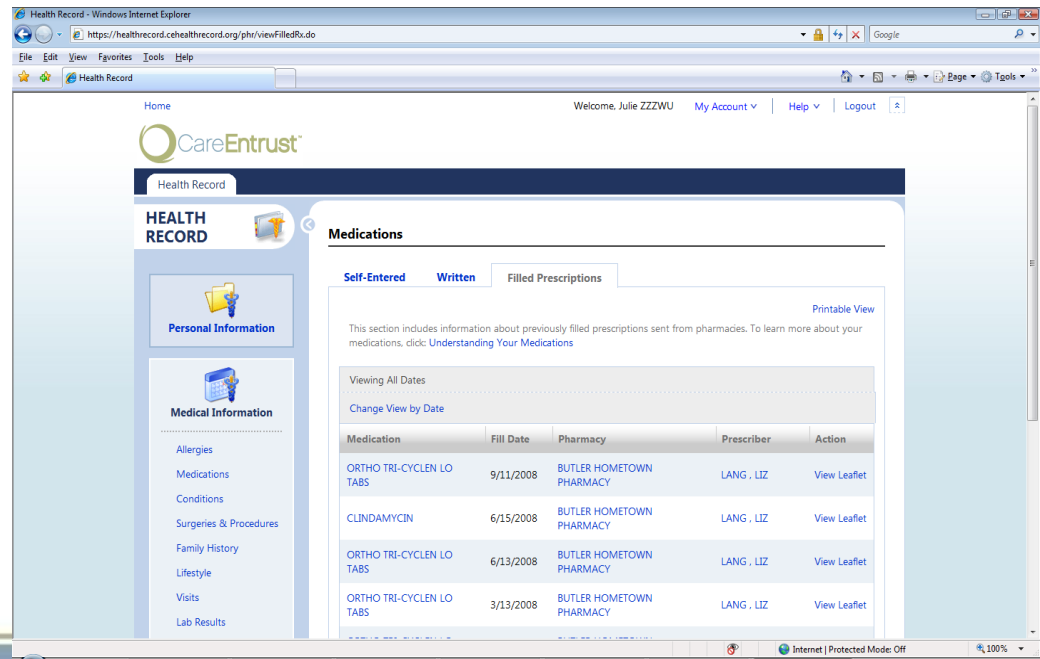
Value Proposition for Consumers/Patients

✓ Ability to access your own health information for <u>better decision-making and improved communications</u> with your health care providers

✓ Maintain your <u>health history in one secure place</u> for convenience and peace of mind in case of natural disaster

✓ Provides <u>quick, composite health history profile</u> for caregivers in critical emergency situations

✓ Ability to <u>grant your health care providers with optional direct access</u> to your record to facilitate safer, higher-quality care

✓ Assists in <u>elimination of redundant paperwork</u> (clipboard) and improvement in the quality of information provided

Intersection with Legal/Policy Workgroup

➢ **Legal/Policy Workgroup Consensus Recommendations to Date**
  - Some form of consent should be required to exchange information through MO's statewide HIE network.
  - Type of consent required may vary depending on use of information:
    - Sharing information for treatment and quality improvement should be first order priority.
    - Public health reporting should be enabled to the extent mandated under current law.
    - Different consent may be required for other uses.
      - Marketing
      - Use by payers
      - Others TBD
  - Regarding sensitive health information, there is a need to address heightened patient privacy concerns while facilitating the availability of necessary information at the point of care.

➢ **Next Steps/Questions**
  - Should MO adopt an opt-in (affirmative written consent) or opt-out model?
  - What uses should be permitted and at what level of consent?
  - How long should consumer consent last?
  - How should minor consent be treated?

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Legal/Policy Workgroup
State Consent Policy Webinar in Review

Matt Duffy & Chris Henkenius
Bass & Associates, Inc.

Deb Bass, Interim Executive Director
Nebraska Health Information Initiative

Steve Larose, VP for External Affairs
VT Info Technology Leaders, Inc.

Anne Cramer, Esq.
Primmer Piper Eggleston & Cramer PC

Micky Tripathi, President
Massachusetts eHealth Collaborative

➢ **Key Policies Reviewed**
- Consent Model
  - Opt-in vs. opt-out and granularity details
- Available information /treatment of sensitive health information
- Permissible uses of health information
- Break-the-glass (emergency access)
- Minor consent

Access Webinar audio recording and materials online at http://dss.mo.gov/hie/leadership/index.shtml

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Consent Model Comparison

Key Takeaway: NeHII, VHIE and MAeHC each employ distinct consent models that take into account their technical architectures, state laws, and consumer/provider preferences.

VHIE

➤ Opt-in.

➤ If patient signs opt-in form, data sharing is enabled between all participating treating providers (patients may not control which providers disclose their information).

➤ No further permission needed by participating treating providers to access data.

➤ Patients receive reminder every 5 years that they have right to withdraw consent.

MAeHC

➤ Opt-in.

➤ 94% opt-in rate.

➤ Patients must grant each provider consent to disclose his/her information to the HIE's clinical repository on an entity-by-entity basis.

  • One pilot allowed a RHIO-wide consent to disclose.

➤ Unless a patient has opted-in, the patient will not show up in the HIE system at all.

➤ No further permission needed by participating treating providers to access data.

➤ Consents must be "refreshed" every two years.

NeHII

➤ Opt-out.

➤ 1.5% - 2.0% opt-out rate.

➤ Opt-out is global (all of a patient's information is excluded).

➤ If a patient has opted-out, the RLS will return the patient's name & demographic info with a note indicating the patient has opted-out of the exchange.

➤ Patients may opt back in under a process that is more strict.

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Project Milestones & Timelines
Operational Planning

Week	Key Topics & Discussions
2/10	➤ Review updated Strategic Plan ➤ Understand examples of existing consumer engagement initiatives ➤ Review project budget
2/24	➤ Finalize Strategic Plan for submission to ONC ➤ Discuss legal/policy implications of consumer engagement principles and strategy ➤ Update from Governance and Technical Infrastructure Workgroups
3/10	➤ Update consumer engagement strategy ➤ Review draft outline/content for Operational Plan
3/24	➤ Develop draft work plan for consumer engagement strategy ➤ Develop draft budget for consumer engagement strategy
4/7	➤ Review and update work plan and budget ➤ Update from Finance and Legal/Policy Workgroups
4/21	➤ Review and comment on draft Operational Plan
5/5	➤ Review updated draft Operational Plan ➤ Review updated work plan and budget
5/19	➤ Finalize Operational Plan for submission to ONC ➤ Determine continuing activities and opportunities for engagement

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Next Steps

- **Review updated Strategic Plan - http://dss.mo.gov/hie/action/index.shtml**
  - Send feedback to kwallis@manatt.com
- **Identify other consumer engagement initiatives for Workgroup review and consideration**
  - Send to ckrebs@primaris.org, 573 424-9174

Next Meeting: Wednesday, February 24th
11:30 am – 1:30 pm
Jefferson City, MO

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